

Richmond & Kingston

ME Group

Serving Richmond & Kingston Boroughs & the surrounding areas

NEWSLETTER

No 2, 2022

Inside — *The Long Covid Self-Help Guide Reviewed* — [REDACTED]'s
Ten Questions — Trampers Scooters — And More...

Rethinking ME — A Very Welcome Development

The Secretary of State for Health and Social Care, Sajid Javid, made a couple of statements on World ME Awareness Day on 12 May 2022. Firstly, he was pleased to welcome the publication of the top ten research priorities for ME/CFS published by Action for ME and agreed by the James Lind Alliance Priority Setting Partnership on ME. Secondly, he announced the government's intention to develop a cross-government delivery plan on ME/CFS for England, aligning with other devolved nations as appropriate, in particular with the Scottish government, to explore areas of potential shared interest and learning, especially in terms of research into ME/CFS.

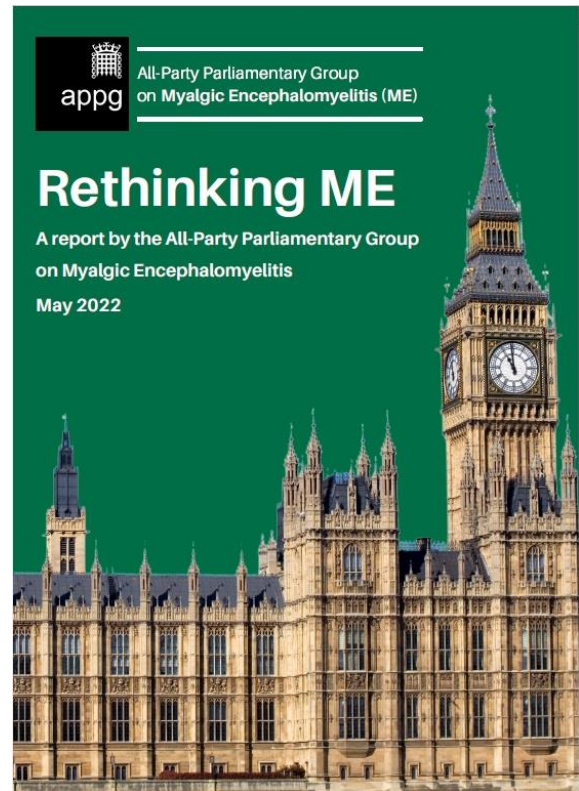
Helplines Information: See Page 15

The Richmond and Kingston ME Group committee invited our members to write to their MPs, sharing information published by the ME Association on the new NICE guidelines, the top ten research priorities for ME and the ME/CFS Biobank, as well as bringing their attention to the All-Party Parliamentary Group on ME meeting on 25 May 2022, in which its report *Rethinking ME* was discussed.

Carol Monaghan, MP for Glasgow North-West and Chair of the ME APPG, said that although there was now a well-documented history of ME, progress in treatment had been hampered by a number of factors, including the outdated opinions of some influential psychiatrists and other healthcare professionals. Many people with ME had described how the treatment they had received had exacerbated their symptoms, and some reported such a decline in their health that they were now bed-bound following medical intervention. Carol said:

Prior to my election in 2015, I had little knowledge of ME. If pressed, I would have given a basic response that it was a condition causing tiredness and lack of energy. The tenacity of my constituents in sharing their compelling testimonies ensured that my understanding was improved. Many other MPs have become involved in the APPG following similar interventions by their constituents, and I commend the ME community and charities on the work they have done in mobilising politicians from every political party to campaign for better outcomes.

Within healthcare, attitudes are slowly shifting, but it is clear that radical action, including mandatory education for relevant health professionals, is needed to ensure appropriate medical intervention and care. This must be coupled with far greater spending on high-quality biomedical research. The new NICE guideline on ME/CFS, published in 2021, has the potential to transform approaches to ME and patient groups and charities will be watching closely to see its impact. The APPG on ME spent over a year taking evidence from patients, healthcare professionals and charities to produce this report. Our recommendations are considered the starting position for government policy, and I hope these are taken seriously by those with the power to make positive change.



Specific Topics of Enquiry

The ME APPG conducted an inquiry to gather further evidence on the challenges impacting people with ME in relation to a number of key areas of service provision:

- ★ Biomedical Research and Research Funding
- ★ Condition Diagnosis and Management
- ★ Children and Young People with ME
- ★ Welfare Benefits and Health Insurance
- ★ Covid-19 and the ME Community

These topics were investigated over the course of five APPG evidence sessions and in further correspondence with ME patients and relevant stakeholders. The purpose of this report was to collate the evidence presented to the ME APPG during the formal inquiry by experts (including health professionals, researchers and social workers) and people with direct experience of ME; to identify and demonstrate the primary issues in the five key areas outlined and to make recommendations to improve the lives of people with ME living in the UK; and to start a dialogue with the UK government, devolved governments and other key stakeholders to develop novel approaches to ME in research, medical care, social care and wider society.

Research Problems

The report said that biomedical research and funding biomedical research into the cause of ME and treatments for ME had been neglected for many years. This has resulted in a weak medical understanding of the underlying pathology of the condition, excessive delays in the development of new diagnostic tests, and a lack of targeted treatments and management approaches. There was a lack of robust epidemiological information on the precise incidence and prevalence of ME in the UK. As such, many vital NHS ME services were missing the information they require to concentrate specialist support where it was most needed. Despite the need for high-quality samples in this often overlooked area, biobanks are struggling for funding and had had to rely on charity research grants to sustain their work.

The problems associated with poor-quality research and a lack of data are exacerbated by misperceptions within the medical field which mean that ME is still not viewed as an attractive area in which to work. However, significant signs of improvement are now visible within the field of biomedical research. The DecodeME study by the ME/CFS Biomedical Partnership, for example, recently secured £3.2 million in funding from the Medical Research Council and the National Institute for Health Research (NIHR).

The ME APPG made the following recommendations to improve biomedical research into both cause and management of ME:

- ★ Coordinated research strategies must be developed to encourage high-

quality ME research. Areas should include biomedical research into underlying ME disease mechanisms, clinical research and treatment trials, support for the development and submission of ME research applications, and incentives for the involvement of early career researchers. Further biomedical research is essential to improve understanding of underlying disease mechanisms in ME, to discover diagnostic biomarkers, and to develop treatment strategies aimed at the underlying disease process.

- ★ Government research bodies should ensure that there is a parity of biomedical research funding between ME and other serious long-term conditions.
- ★ Centres of ME research excellence should be established to drive forward the development of effective treatments, learning from the projects of other nations, including the initiatives of the US National Institutes of Health, now incorporated into the National Academy of Sciences.

Regarding diagnosis, symptom management and medical services, the report says that patients experience a lack of health professional awareness of how both to diagnose and manage ME, which has had a significant negative impact on them. For many individuals, the most difficult aspect of coping with ME, other than the associated debilitation, is the failure of professionals to take the condition seriously. People with ME often report being disbelieved or treated poorly when they raise any concerns. There are concerns that some medical professionals will act in contravention to the new NICE guideline by continuing to prescribe Graded Exercise Therapy to patients under another name. Poor ME awareness amongst healthcare professionals, alongside the lack of a laboratory diagnostic test, has resulted in late diagnoses and misdiagnoses.

Severe and very severe ME affects approximately 25 per cent of people with ME. This cohort are housebound or bedbound at some stage in the progression of their illness, often requiring a wheelchair and unable to do basic household tasks without assistance. Most of these patients are unable to access primary or secondary care for a number of reasons and, as a result, many people with severe ME lose all contact with NHS support and social care.

Main Recommendations

The ME APPG recommended the following steps to be taken for the ME community:

- ★ Health professionals should follow the recommendations in the new NICE guideline on ME/CFS and ensure that ME patients do not undergo any form of GET as treatment. Patients should instead be encouraged to stay within their 'energy envelope' when engaging in any mental or physical activity.
- ★ Updated training on ME which is based on a biomedical model of causation should be provided for both pre- and post-registration health

professionals. The Royal Colleges should ensure that those working in primary care and relevant medical specialities receive postgraduate training on ME. Medical schools should provide compulsory ME training for undergraduates.

- ★ Health service commissioners should carry out a review to identify the current level of service provision for people with ME and take steps to ensure that local ME service provision is carefully planned, resourced and implemented. This should include multidisciplinary hospital-based referral services containing the full range of health professionals that are recommended in the new NICE guideline.

ME can affect both children and adolescents. An epidemiological study showed ME to be the most common cause of pupil long-term sickness absence from surveyed secondary schools. Paediatricians do not always have the experience or confidence necessary to diagnose ME in children and adolescents. Without a prompt clinical diagnosis, the parents or guardians of a child with ME are left without formal medical evidence of their child's condition and are open to intense scrutiny. Munchausen Syndrome by Proxy (MSBP) is a mental illness and form of abuse whereby a mentally ill person falsifies or causes an illness or injury in a person under his or her care. Though MSBP is difficult to quantify and has been subject to debates regarding definition and prevalence, cases are rare. However, following the decision in 2001 by the Royal College of Paediatrics and Child Health (RCPCH) to replace MSBP with a novel umbrella term, Fabricated and Induced Illness (FII), hundreds of families of children with ME have faced child protection investigations following allegations of FII.

The ME APPG supports the recommendations in the new NICE guideline with regards to the basic principles of symptom management, safeguarding and care for children with ME. The ME APPG also makes the following recommendations in light of evidence provided by health professionals, social workers, policy makers and the parents of children with ME:

- ★ Health commissioners should ensure that all children and adolescents with ME have access to correctly trained hospital paediatricians and long-term community services.
- ★ The RCPCH should ensure that all paediatricians receive specialised training on recognising, diagnosing and managing children and adolescents with ME to avoid misdiagnosing FII.
- ★ An independent second medical opinion obtained by a parent or guardian of a child with suspected or confirmed ME should be taken into account in any decisions regarding diagnosis, treatment or welfare.
- ★ The Chief Social Worker (or equivalent in the devolved nations) should ensure that the guide for social workers working with children and young people with ME or suspected ME (developed by social workers in partnership with Action for ME) is shared with all social care departments to

ensure that children are not unnecessarily subjected to child protection procedures due to a lack of understanding of ME.

- ★ All children and young people with ME should have a care plan, in accordance with national guidelines and/or statutory requirements, that combines education and health.
- ★ Schools, colleges and universities should make learning and assessment modifications for students with ME. Home-based tuition and remote interactive lessons should be provided for those who are unable to attend classes.

Welfare Benefits

Welfare benefit rejections is another big problem for patients with ME. It is clear from the evidence presented to the APPG that too many of them are being refused Employment and Support Allowance (ESA) and Personal Independence Payment (PIP) by the Department for Work and Pensions (DWP). Those who are refused ESA or PIP can take the decision to appeal, and many people with ME who have taken this action have gone on to win their case, indicating flaws in the initial system.

However, some are unable to pursue this avenue because going through the complex appeals process, which requires a considerable amount of preparation from the claimant, would exacerbate their symptoms. As a result, many people with ME are existing without the financial support they need. Another ongoing issue that ESA claimants face is with the associated complex paperwork (that is, the ESA50 questionnaire). People with ME often require additional support to complete this paperwork due to the cognitive dysfunction they experience, and it may take time to find someone to provide support before the submission deadline.

People with ME have been pressured by their private health insurers to undertake a course of GET, despite detrimental effects, in order to keep their insurance-based health and disability payments. Additionally, some health insurers have required people with ME to participate in inappropriate and potentially harmful medical evaluations to determine their work capabilities and assess their claims.

After considering the evidence provided to the ME APPG by health professionals, social workers, benefits advisers, policy makers and people with ME, the APPG makes the following recommendations with regards to welfare benefits and health insurance:

- ★ The DWP should ensure that people with ME have fair and equitable access to welfare benefits by taking steps, firstly to account for the impact of ME on the ability to engage with the application process, and secondly, to minimise potential negative health effects associated with medical assessments. These steps should involve ensuring that claimants can carry out activities repeatedly and reliably without risking adverse health impacts

and are scored fairly; accepting supporting information from accredited medical professionals, other health and social care professionals and carers; providing an extension for completion of ESA paperwork in line with those provided for PIP applications; and ensuring that medical assessors understand and work within the NICE guideline which explicitly states that GET should not be recommended or required.

- ★ Health insurers should not require people with ME to undertake GET, Cognitive Behaviour Therapy or health assessments that require levels of activity which could produce adverse health effects.

ME and Corona Virus Symptoms

Whilst both Long COVID and ME are heterogeneous conditions, they exhibit several clinical and pathological overlaps. Both conditions present fluctuating and multisystem symptoms, and the most common Long COVID symptoms — extreme fatigue, cognitive dysfunction, problems with pulse and blood pressure regulation, and sleep disturbances — are experienced by people with ME. As a result, people with Long COVID have, in some areas across the UK, had access to ME services for help with condition management.

In the UK, a great deal of biomedical research is now being funded into both the cause and treatment of Long COVID, presenting an opportunity for the research community to develop a better understanding of other conditions which may develop post-virally, including ME, and finally put an end to the narrative that these conditions are psychological in nature.

It is important that people with post-viral conditions receive suitable care and support. The ME APPG makes the following recommendations drawing on the expertise of the health professionals, researchers and people with ME who gave evidence:

- ★ Long-term health planning, policy and financing should consider the high number of individuals experiencing Long COVID.
- ★ Health service commissioners should ensure that there is cooperation between ME and Long COVID clinics to maximise patient benefit.
- ★ The National Institute for Health Research should ensure that funding is provided to Long COVID research projects that include ME patients as a comparative group.
- ★ Further publicly funded biomedical and clinical research should be commissioned to investigate and compare a range of post-viral conditions, including ME.

To Conclude...

The APPG report says that people with ME require major cultural change to take place within all professions associated with their care and support. Sadly, false and outdated understandings of ME still circulate within medical and public discourse, making it more difficult, and often impossible, for people with ME

to access the services to which they are entitled. Whilst there is still a long way to go, the ME community and their advocates within the medical profession and wider society have made significant strides in challenging erroneous understandings and pressing for improved care. With the recent publication of the new NICE clinical guideline on ME/CFS, the APPG is confident that a turning point has been reached.

The authors of this report see these recommendations as a starting point on which to build creative strategies across the governments of the UK, service providers and research institutions for the transformation of our society's approach to ME. Furthermore, they wish to see the UK take both a pioneering stance towards ME research and a compassionate attitude towards people with ME at a time when we are seeing an increasing trend in the development of ME-like symptoms as a result of COVID-19.

The Richmond and Kingston ME Group committee wish to thank all of you who e-mailed your MP in support of these reforms for the fair and right treatment of our condition.

Book Review

██████████ reviews *The Long Covid Self-Help Guide: Practical Ways to Manage Symptoms* by the Specialists at the Post-Covid Clinic, Oxford (Bloomsbury, 2022).

* * *

We have now welcomed our first Long Covid sufferers to the ME Group, both those diagnosed with Long Covid and with ME (following Covid) and, of course, some of us have Long Covid and ME. This is a practical guide for people with Long Covid, addressing the management of some key symptoms. These symptoms are horribly familiar. So what does this book say, would we concur with the advice, and is there anything in it for people with ME?

Each of the book's chapters covers a different aspect of Long Covid written by a specialist from the Oxford clinic. There are many quotations from people with lived experience, and the suggestions are illustrated with examples, which make it both an easier read and more directly relevant. After describing Long Covid, they examine fatigue, breathlessness, sleep disturbance, psychological considerations, loss of smell, balance issues, and finally returning to exercise, work and dealing with daily life.

The first reference to ME comes on the second page of Chapter I. I found this rather reassuring. In this chapter they acknowledge the problem of definition, its different manifestations and fluctuating symptoms, the more surprising finding that mild Covid cases can become Long Covid too. They also mention four competing theories about Long Covid (auto-immune, inflammation,

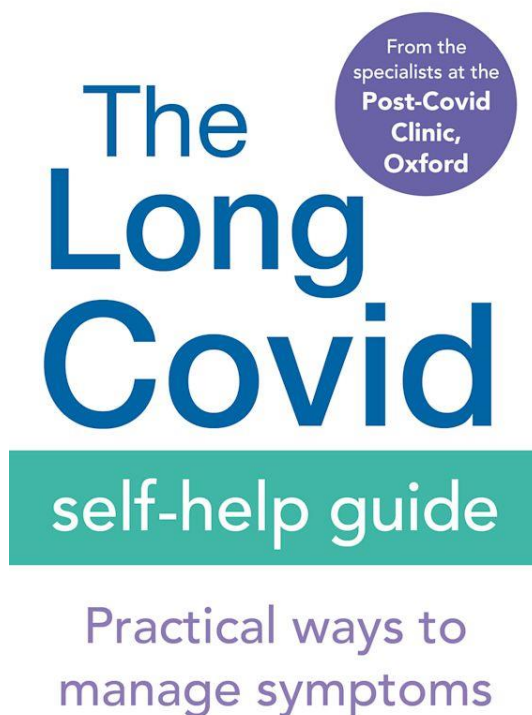
neurological damage, and multi-organ damage from micro-clots). They describe the common symptoms as disabling fatigue (and PEM), brain fog, breathlessness/cough, sleep disturbance (and unrefreshing sleep), low mood and anxiety, smell disturbance, chest pains, palpitations/ rapid heart rate, dizziness, gut issues, hair/nails/skin changes, and fever. Sound familiar?

They define fatigue as different from tiredness (hooray!), and use the analogy of a mobile phone battery. Their advice is to prioritise, plan and pace. They talk about the value of alternating activity and rest through the day, switching between physical and cognitive tasks, and working out when you need to stop (and stopping!). They discuss daytime rest (not just low-level activity, and suggest you might nap but not sleep). There is a very helpful and detailed section on establishing your baseline. They do describe 'pacing up', but explicitly reject GET, and they talk sensibly about fluctuations and flare-ups/setbacks.

The chapter on breathlessness starts with a review of the types of oxygen interventions severe Covid patients faced and a description of how breathing works. I was interested to learn that shallow breathing (from the chest) consumes much more energy than diaphragmatic breathing (deep breathing from the abdomen) as well as activating the fight/flight response. Breathlessness can be severe and come from physical damage from Covid, but can arise out of a shallow breathing pattern learnt during Covid while managing chest pain, and perhaps perpetuated through anxiety, posture etc. There is clear and detailed advice on how to assess your breathing, and strategies and techniques for managing breathlessness and air hunger in various situations.

While the origins of breathlessness or loss of smell after Covid are well understood, those of sleep problems (as with fatigue) are usually not (although sleep apnoea is an occasional outcome of Covid). Sleep is controlled by sleep pressure (tiredness building over the day) and the body clock (circadian rhythm stimulating melatonin from dusk). These can be interrupted by daytime sleeping and blue light from electronics in the evening, for example. The sleep cycle (through different types of sleep) also determines how rested we are. They suggest reasons for poor-quality sleep and practical suggestions to develop a good sleep routine that may help.

Returning to physical activity and PEM is covered, looking at the individual start point and classifying activities by exertion (so you can plan better). The



GREEN TREE

suggestion is gradually to increase, but also to watch for PEM (as opposed to normal fatigue after exercise) and to avoid overdoing things.

Psychological considerations cover the issues we are all familiar with: including feeling let down by medics, the impact of encountering disbelief, and fear about the future creating long-term stress. They discuss the need to adjust to being unwell (drop perfectionism!), and to learn to deal better with stressors. They have a set of suggestions for supporting mental health through this process.

Regaining your sense of smell for most is just a matter of weeks, but for 10 per cent there may be nerve damage and recovery takes longer (up to two years). With nerve damage, the issue can be lack of smell or, for the unlucky, smell is awful. Smell training is possible (!) and is described.

There is then a bucket chapter for other symptoms (brain fog, dizziness, palpitations, gut issues and more). There are some suggestions for management of these, but they are generally less well developed than the rest. Perhaps the most helpful discussion here is about dizziness which might be of interest to those of us with ME who suffer from vertigo, but have had no advice on managing this.

Finally, there is a chapter on returning to work. I think this is helpful in exploring the relevant issues, the resources to help you consider this, and how to manage the re-entry process.

There is an underlying belief in the book that life will broadly return if you follow the suggestions, and for many people with Long Covid this will be true; recovery is the norm albeit very slow for some. I worry that for those for whom Long Covid becomes ME this certainty may be less helpful. But overall, I felt the advice was quite sensible and that I would have benefitted from a lot of it when I was newly ill.

Thread 6, by

A thread through which I gained hope
of a new connection — my previous life cut away
when I was unable to move — to live life
within it

and a motif chosen, drawn onto the fabric
of a dull day — pierced by the needle trailing
a black thread — marked out a violent conflict
within its contours.

But, this war, my war, though without bloodshed — my crewel
knows is not without pain, and probes the fabric

to draw along a new thread — allowing
the moments to slip behind me effortlessly

as suddenly, the resentful beast within
my breast is now altered — now
contentedly breathing in time with me.
... for a while.

What Our Members Are Doing

Done anything exciting, inspiring, interesting? Although ME does its best to make our lives miserable, this does not prevent us from trying to make our lives as fulfilling as we can. So do let us know what you're up to.

██████████ has continued with her painting, and has produced quite a few new ones, including a delightful snail disc which she's holding here. Don't forget her splendid book of poetry and paintings. Lois can be contacted at ██████████.



██████████ had an article on Sir Bernard Pares, the British liberal 'Russia Hand' who unexpectedly became enamoured with Stalin in the 1930s, published in the 24 June 2022 issue of the *Weekly Worker* paper. A longer version of this article will be included in his forthcoming collection of essays, *Confronting the Myth*, which he is currently preparing for publication.

Ten Questions

This time answered by ██████████.

- 1) **How long have you had ME?** Twelve years.
- 2) **What was the trigger that started it off?** Pernicious Anaemia.
- 3) **What is the worst thing about having ME?** The inability to exercise and not having volition over my own life.
- 4) **Has anything good come of it?** I've learnt to stop taking it personally! I've also learnt to enjoy being more creative, developing my interest in

embroidery and writing, though I'm still limited by fatigue. I also meditate daily when I can and I follow the on-line Gaia House Dharma talks and meditation (Buddhist).

- 5) **What treatment (prescribed or alternative) has helped the most?** Avoiding food that cause digestive upset/inflammation, taking vitamin supplements, having regular rests three times daily with belly breathing exercises, Nuad Thai Massage weekly, stretching floor exercises nightly (through contact with an ME physiotherapist), aqua physio gentle pool exercises in Morden.
- 6) **And which was the most useless or did the most harm (to you or your pocket)?** Naltrexone seemed to make my fatigue worse. CBD had minimal affect.
- 7) **What do you like doing on a good day?** I go out for coffee or eat out with friends (by car).
- 8) **Do you have any tips for getting through a bad day?** Rest, read, watch drama and sport on TV.
- 9) **What is the worst thing anyone has said to you?** Nothing is said, as most people look past you when you tell them the nature of your illness.
- 10) **And the best?** My husband saying that Buddhism is helping me.

Extra questions:

- 11) **Where would you like to be now?** On the mobility scooter that I haven't bought yet!
- 12) **Tell us a joke/mantra/quote:** Live in the present.

Trampers Mobility Scooters

Although mobility scooters greatly help our freedom of movement, they do have their limitations. Their use is largely restricted to roads and solid paths and they can have problems when surfaces are rough or uneven.

Trampers are all-terrain mobility scooters which able to solve these limitations. They will take you where you want to go and, as they're electric, with no emission! There are four and three-wheeled versions, capable of taking their riders over hill and dale, or just to the shops. They give their users their independence again, enabling them once more to accompany their friends and family on trips to the countryside.

If you would like to try one, there are over 100 available for hire at sites all around the country, including some of the National Trust's premises, or the charity Countryside Mobility South-West (<https://countrysidemobility.org>), where you can join by completing a one-page membership form. It costs £2.50 for a two-week taster or £10 for the whole year.

██████ decided to have a taster recently at Hatchlands Park in Clandon,

Surrey, which is run by the National Trust. You do not have to hold National Trust Membership in order to use their Trampler vehicles. All you have to do to book is ring or e-mail the specific place you wish to visit within the National Trust and the staff can advise about available vehicles to hire, free of charge.

██████ was recommended by a family member to download the National Trust App to help her use available Trampler vehicles in her local area. The family member had recently suffered a stroke but wanted to still get out and about in the fresh air, despite limited mobility. The National Trust were extremely accommodating, helping her to book available vehicles and advising about appropriate routes, etc. ██████ downloaded the National Trust App on her Smart Phone and found it to be very easy to navigate. The app requires you to set up a simple profile and is free for anyone to register. The home page of the app takes you straight to your local National Trust places to visit. You can then click on the property of your choice and find all the basic information. There is a tab called Facilities and Access for each National Trust place/property. Here, you can find out toilet facilities, distance from car park to entrance, terrain type, accessible routes and specific vehicle hire availability.

██████ had great fun, riding her all terrain Trampler vehicle at Hatchlands Park. She was able to book the Trampler vehicle, for their afternoon session (one to four o'clock), just 48 hours after e-mailing hatchlands@nationaltrust.org.uk. She was amazed at how smooth the ride felt and was very simple to operate. She could enjoy a country walk for once, without severe pain, fatigue and subsequent PEM. The vehicle prevents you getting dirty, so no muddy boots or soggy trouser legs. It's an all-win situation, you see!



As mentioned in a previous edition, ██████ had the opportunity to take



his daughter to the Eden Project in Cornwall in July 2021. At first, he thought he wouldn't be able to do much in that big complex as his walking was very limited. However, he decided to have a taster with a Trampler and signed up with the Countryside Mobility (it only operates in the South West of England though) for a couple of weeks. He went nearly everywhere in the project with his daughter walking alongside (he couldn't put the

Tramper on the tree-top walk, alas, as it was too high and narrow!) and found the scooter comfy and powerful.

The Accessible Countryside website informs where you can find different areas of the countryside in England and Wales that are accessible for wheelchairs. In these areas you either will have to bring your own mobility scooter or rent one where available: www.accessiblecountryside.org.uk

One good thing about this website is that it has the Main Menu on the right-hand side, where you can navigate until you find a section 'Specialist Wheelchairs and All-Terrain Mobility'. This section gives a list of the companies renting all-terrain scooters in the UK and other European countries, in case you have the lucky opportunity to go abroad.



Reproduced with permission from Shantel's Pencil Art: <https://www.facebook.com/shantelspencilart123>

Contingency Fund

Please remember that you can apply for help from the Group Contingency Fund not only to pay for taxis or other travel expenses to see your GP/Consultant, but also to pay for their medical report and your medical information in the NHS system in order to support your benefits application. We

have received lots of feedback about the difficulties of applying for PIP and other benefits; therefore, we consider that it is essential that you obtain an updated report from your GP, which usually costs between £25 and £50. Remember that this fund can also be used for such things as attending Group meet-ups and benefit assessments, or in a family emergency.

If you wish to apply for a payment from the fund, please contact any member of the Committee. The maximum you can claim is £50 per year and you will need to submit the receipts with the application form. If your circumstances are such that you need the money in advance because you're running low on funds or are needing more than £50, or if you aren't able to provide a receipt with your application, please contact our Treasurer to discuss your situation before you apply.

Benefit Queries and Helplines

If you are thinking of applying for Employment and Support Allowance (ESA), Personal Independence Payment (PIP), Attendance Allowance (AA), Universal Credit (UC) or any other benefit that applies to your circumstances, please note that [REDACTED] ([REDACTED]) and [REDACTED] ([REDACTED]) are available for any question you may have regarding this matter. You should contact one or the other of them before you request your application form from the DWP, as once you do this you have only four weeks to complete it and you may need more time to do this or to obtain medical evidence to support your application. [REDACTED] and [REDACTED] can also send any queries on your behalf to Ken Butler, the benefits advisor from Disability Rights UK, who will attempt to answer them.

There is an excellent group on Facebook for anyone with ME who is applying for benefits — UK ME & Chronic Illness Benefits Advice, at https://www.facebook.com/groups/278260135547189/?multi_permaLinks=3943774848995681. If you don't have a Facebook account, please contact [REDACTED] or [REDACTED] and your query will be referred to this group.

The Action for ME's Welfare Advice and Support Service provides free confidential advice over the phone on welfare benefits, disability discrimination and employment issues to people affected by ME. It is open on Monday to Friday from 10.00am to 4.00pm. Call 0117 927 9551 or e-mail welfare @actionforme.org.uk.

The ME Association runs ME Connect. It provides support for people with ME and those who live with or care for them. It is open every day of the year between these times: 10.00am to 12.00 noon, 2.00pm to 4.00pm, 7.00pm to 9.00pm. The telephone number is 0844 576 5326. There is an e-mail contact at meconnect@meassociation.org.uk.

The Disability Law Service offers free advice on 020 7791 9800, and on-line advice can be obtained via its website <https://dls.org.uk/free-advice/online-advice/>.

Richmond and Kingston ME Group Committee		
Chair	Vacant	
Secretary	Vacant	
Treasurer	██████████	████████████████████
Membership Secretary	██████████	████████████████████
Project Coordinator	██████████	████████████████████
Committee Member and Group Library	██████████	████████████████████
Committee Member	██████████	████████████████████
Social Secretary	██████████	████████████████████
Twitter	██████████	████████████████████
Newsletter	██████████	████████████████████

The following members are not on the Committee but carry out important work for the Group.

Facebook	██████████	████████████████████
Interview Tape Recorder	██████████	████████████████████

Group Website — <http://www.richmondandkingstonmegroup.org.uk>

Facebook — <http://www.facebook.com/pages/Richmond-and-Kingston-ME-Group>

Twitter — @randkmegroup

Disclaimer: While as a Group we prefer and endorse the term ME (Myalgic Encephalomyelitis), there may be times when articles printed from other sources contain the term Chronic Fatigue Syndrome. Any information in this newsletter must be checked by you, as we cannot accept responsibility for it. The use of alternative medicines or therapies is a matter for the individual. The views expressed are personal and not necessarily those of the Richmond and Kingston ME Group. Reference to any products or services is for information only, not an endorsement.

	<p>The Richmond and Kingston ME Group is grateful for the generous financial assistance that has been provided by Waitrose.</p>
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